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ABSTRACT

This report is based upon a review of current Idaho policies, laws, regulations, and practices that have affected the lives of people with developmental disabilities, interviews with a sample of administrators and staff members representing government, voluntary agencies, self-advocacy groups, and provider agencies, and insights gained from various meetings and presentations on self-determination. It begins by explaining the four basic principles of self-determination: freedom, authority, support, and responsibility. The growing self-advocacy and parent advocacy movements within Idaho are described, along with the movements towards supported employment, deinstitutionalization, supported living, early intervention, and greater family support. Barriers to people achieving self-determination are identified, and recommendations are made to improve the lives of people with developmental disabilities. Recommendations include: (1) look at ways to strengthen the collaboration among people who care about individuals with developmental disabilities; (2) take what has been learned about how people with developmental disabilities can create the lives they want within their communities and find ways to pilot additional opportunities for learning; (3) make individuals with developmental disabilities and their families partners in creating the policies which guide the system of support they rely on; and (4) revise Medicaid-funded developmental disabilities services. (CR)

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Are We Swimming in the Right Direction?

From Dependency to Self-Determination for Idahoans with Developmental Disabilities

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June, 1998

Prepared by
Dennis Harkin

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ABOUT THE AUTHORS

Dennis Harkin has worked to serve people with developmental disabilities for the past 25 years. For 10 years he was the Director of services for people with developmental disabilities in Wisconsin, where he provided leadership in the development of programs such as Family Support, Home and Community Based Services Waivers, Supported Employment, Community Supported Living Arrangements, and more recently Participant-Directed Services. He now works with local, state, and national agencies through his own consulting agency, *A Simpler Way.*

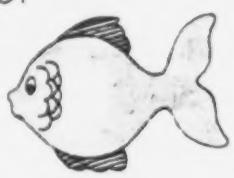
Throughout his career Dennis has worked directly with people with disabilities, members of their families, advocates, providers, and public agencies in an attempt to create community among individuals with developmental disabilities and those who share their lives.

Dennis Harkin
A Simpler Way
5826 Bartlett Lane
Madison, WI 53711

Donald L. Shumway is Co-Director of the Robert Wood Johnson Foundation's National Program on "Self-Determination for Persons with Developmental Disabilities." He has been managing grants and technical assistance to states and individuals on self-directed supports and alternatives to cost-cutting-centered managed care.

Prior to this, Mr. Shumway served as Director of the New Hampshire Division of Mental Health and Developmental Services for twelve years during which time he had overall responsibility for the Division's $200 million service system. Under Mr. Shumway's leadership, New Hampshire achieved the first closing, nationally of all institutional services for persons with developmental disabilities, through the development of a highly community-based individual and family support system.

Donald L. Shumway
The Institute on Disability
The Concord Center
10 Ferry Street, Suite 10
Concord, NH 03301



ABOUT THE ARTIST

Barrie Ernst's pen and ink drawings have a distinct style. The little crooked line expressions are unique to her approach and due to the effect of rheumatoid arthritis to her hands. However, the drawings still show warmth, understanding, and love for the mountain West. She is particularly fond of remote and desolate places long abandoned by pioneering people. Whether a house, a corral, or a wagon wheel, Barrie manages to capture a historical memory in her unique way.

ACKNOWLEDGEMENTS

A special thanks to The Robert Wood Johnson Foundation, The Bureau of Developmental Disabilities, The Center on Disability and Human Development, and most Importantly thanks to all of the people with disabilities, parents of people with disabilities, providers, and advocates, who contributed to the contents of this report.

Introduction

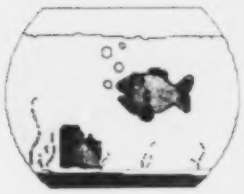
This report is based upon impressions gathered between December, 1997 and April, 1998 in Idaho. It is not intended to be a comprehensive review of Idaho's system of services for people with developmental disabilities.* Rather, it is intended to inform, to stimulate dialogue, and to encourage further action in helping Idaho's citizen's with developmental disabilities exercise greater freedom and responsibility in their lives.

The impressions and recommendations expressed herein are those of the author, and do not necessarily reflect the point of view of Idaho Council on Developmental Disabilities, the agency which requested this report. The report is based upon a review of current Idaho policies, laws, regulations and practices which have impact on the lives of people with developmental disabilities; upon interviews with a sample of administrators and staff members representing government, voluntary agencies, self-advocacy groups, and provider agencies; and upon insights gained from various meetings and presentations on self-determination conducted in Boise, Moscow and Pocatello. Donald Shumway, Co-Director of the Robert Wood Johnson Foundation National Program Office on Self-Determination, participated in two of the meetings described above, and contributed to this report.

The report is written in a casual and informal style, in hopes of fostering dialogue and action among people with developmental disabilities in Idaho and their fellow citizens, many of whom I have had the pleasure of meeting over the past six months.

* A still relevant review of that nature was completed in October, 1992, by the Human Services Research Institute, entitled *Visions of the Future: Improving Developmental Disabilities Services in Idaho.*

What is Self-Determination?



"Why is there a question about whether or not people should have their freedom?"

Jonathan Dillard at a Self-Determination meeting in Boise

What is our answer to Jonathan's simple question? Why, in the country which more than any other in history takes pride in its belief in personal freedom, is there even the slightest question about whether people with developmental disabilities ought to be free to create the kind of lives they wish to live?

People without developmental disabilities would not consider giving control over their lives to committees of experts, even good and caring experts, who would decide where they would live; with whom they would live; where they would work or even whether they would work; and where and with whom they would play. Yet, for people with developmental disabilities across the United States, including those who live in Idaho, the freedoms we hold most dear in this country have been severely compromised.

The basic idea driving self-determination is the notion that having a significant disability need not and should not diminish people's freedom to pursue their own future, to create their own lives. Over the past 150 years we have moved from a system of institutional care which historically deprived people of nearly all of their freedoms, to a more benevolent system of community services and support, developed and controlled by government and provider agencies. The movement towards self-determination is a natural next step in our journey together.

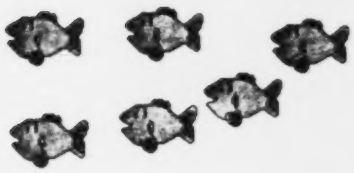
Self-determination allows people and their families and friends, in conjunction with support from others, to be the decision-makers concerning the support they need. It is based on four basic principles:

- the Freedom to plan a real life;
- the Authority to control a limited amount of resources;
- Support for building a life in one's community; and
- Responsibility to use public dollars wisely and to exercise citizenship in one's community.

Based upon these principles, a system is emerging across the country in which people and their families determine how an individual budget will be used in support of a place to live, obtaining an income, meeting personal needs, and enjoying life. It is a cost-effective system; maintaining, strengthening, and for some people recreating ties to the community. It is a system in which providers of services and supports are encouraged to be flexible, creative, and entrepreneurial.

Self-Determination in Idaho: A Foundation to Build Upon

Self-Determination is a term which represents the ideas of freedom and responsibility described in the introduction to this report. It is not a fad. It is not the latest politically correct movement. The words are a reflection of what we are learning together across the country, and in Idaho.



A foundation has been laid to support the idea that people with developmental disabilities in Idaho can experience Self-Determination in their lives."

As in other states, the system for services and support to people with developmental disabilities in Idaho has evolved over time in a piecemeal fashion. It is a system which in some ways functions well, and in other ways seems to get in the way of helping people obtain the support they need. The purpose of this report is not to evaluate Idaho's entire developmental disabilities services system. It is intended to highlight those elements of the system which tend to either facilitate or impede the evolution towards people with developmental disabilities being able to lead their lives with the same degree of freedom as their fellow citizens.

The idea that people with developmental disabilities can be supported within our current public funding in a manner which does not compromise basic human freedom has not emerged from a vacuum. It is based upon our thinking, learning and acting together. In reviewing policies, programs and procedures guiding services to people with developmental disabilities in Idaho; and in meeting people who administer, staff or receive those services, it was clear to me that a foundation has been laid to support the idea that people with developmental disabilities in Idaho can experience Self-Determination in their lives.

The foundation for this evolution will be described below under two broad categories: people and attitudes; and programs and policies.

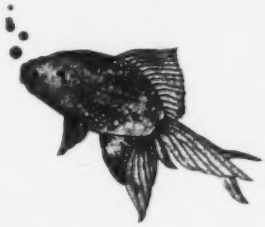
People and Attitudes

Throughout the interviews and seminars conducted over the past 6 months I had the opportunity to meet a cross section of Idaho's current and future leaders in the field of developmental disabilities: administrators and staff of government, providers, advocacy and voluntary associations; people with disabilities; parents and siblings of people with disabilities; an informed legislator; and university and high school students. It is people who will change systems, and the following "people strengths" can be built upon within the context of self-determination:

- There is a growing self-advocacy movement within Idaho, led by the People First organization. Across the country, it is people receiving services and support from our system who, like Jonathan Dillard, are asking, "Why is there a question about whether or not people should have their freedom?"

- There is a growing parent advocacy movement within the state. Idaho Parents Unlimited, for example, has been able to bring parents together and to the table to influence the school systems towards increasing inclusion, and the Department of Health and Welfare administered system towards increasing responsiveness to the needs of families who have a child with a disability and to adults with disabilities.

- The Partners in Policymaking initiative, sponsored by the Idaho Council on Developmental Disabilities, has been helping parents and adults with developmental disabilities understand both their responsibilities and potential leadership capacity as informed citizens in the arena of disability policy.



- There is active advocacy, planning, information-sharing, and coalition building coming out of Idaho's Council on Developmental Disabilities, Protection and Advocacy Agency, the State Independent Living Council, and University Affiliated Program. While this collaboration towards system change among these agencies may be taken for granted, the degree of cooperation and consensus among these groups in Idaho is much greater than experienced in many other states.

- There is an openness to change and considerable experience and competence within various central and regional offices of the Department of Health and Welfare. As the former Director of a state agency in Wisconsin, I am aware that openness, competence and flexibility are not always terms used to describe state bureaucracies. These characteristics were reflected in:

"Idaho has a growing number of people in all parts of its system who are expecting the system to become more responsive to the people it serves."

- A commitment to seek input from the community on changing the system, and a history of acting upon that input. This is perhaps best illustrated by the effort initiated in 1992 by the Bureau of Developmental Disabilities Services to review the performance of the system. This review led to the implementation of significant changes in the operation and privatization of Developmental Disabilities Agencies, in creating independent case management, in making supported employment more available, and in improving the Medicaid home and community-based services waiver. A similar, but broader in scope systems change opportunity exists today within the current Medicaid Reform effort, which also has a commitment to seek input from outside of the state bureacracy.

- Recognition of competent and highly respected staff within the Department, specifically within the Bureau of Developmental Disabilities; within the Access unit in the regional office in Lewiston (that does not mean that similar competence does not exist in other regions, only that during the Moscow seminar on self-determination a number of people pointed out how responsive that particular office has been); and within staff of the Medicaid Division who have worked on issues specific to people with disabilities.

- There is a broad network of provider agencies, a number of which were mentioned for their particular expertise, willingness to be more flexible and responsive, and commitment to the people they serve.

- There is a gradual acceptance by Idahoans that disability is a natural aspect of life, and a growing understanding of the need to strengthen communities by making them more accessible to and supportive of people with disabilities.

Idaho has a growing number of people in all parts of its system who are expecting the system to become more responsive to the people it serves, are increasingly conscious of the importance of people making decisions about their own life, and have the energy and commitment to work towards making the elements of self-determination a reality.

Programs and Policies

Most of what we have learned about self-determination has been derived from what we have learned from people with disabilities as services and programs have evolved. Thirty years ago, it would have been inconceivable to think of the concept of self-determination within a service system which relied almost exclusively on large institutions. Most initial community programs were developed on a "care and treatment" model which had little understanding that people with significant disabilities could be partners, much less primary decision-makers in deciding how to receive the support they need to lead a life worth living.

Over time, we learned from people with disabilities and their families that people could receive the special support they need to account for their disabilities in very typical ways through programs such as supported living, supported employment and family support. In Idaho, this accumulation of learning is reflected in at least the following programs, policies and practices:

- The downsizing of Idaho State School and Hospital; Idaho has been among the leaders in this country in the movement away from the use of large institutions.
- The continued development of supported employment, with a more recent emphasis on consumer control of funding for and choice of agency to provide job-related support;

- The gradual development of supported living;
- The Infant and Toddler Program, which provides support to children and their families in a manner responsive to needs identified by the family;
- The family support program, which, though small in size, creates an important laboratory for learning about flexibility and self-determination;
- The Home of Your Own Project, which is not only based upon supported living, but has taken an additional step in helping people with significant disabilities become homeowners;

- A small, but growing number of examples of inclusion of children with significant disabilities in regular classrooms;

- *Independent* case management, which is an integral part of any system in which people can get support to choose how they want to use public funding to best meet their needs;
- A relatively small, but growing Medicaid Home and Community-Based Services Waiver program, which has the potential to expand and to offer more flexible services, tailored to how people want to have their support provided; and
- An exceptional effort on the part of the Department of Health and Welfare (particularly the Bureau of Developmental Disabilities Services), the Idaho Council on Developmental Disabilities, the Idaho Center on Disability and Human Development, and others to create and disseminate materials about programs, about people's rights within those programs, and particularly about how Idahoans can access those programs and use them in a consumer-directed manner as currently possible. The handbook entitled *Community Supports for People with Developmental Disabilities* and the manual *Finding and Keeping a Job* are examples of the kinds of materials which help people understand the system, and help prepare people to exercise more control over their lives.

These programs, policies and activities have created an environment within which Self-Determination may evolve. The pace at which it does so will depend upon many factors, including how the concerns described in the following section are addressed.

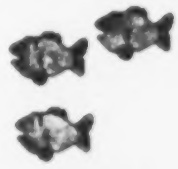
Barriers to People Achieving Self-Determination

Just as the learning which will enable self-determination to evolve is based on Idaho's history, so are the current barriers to people having more freedom in their lives. The most significant obstacle to taking the next steps towards helping create a more cost-effective and person-centered system of support for Idaho citizens with developmental disabilities is the historical bias towards using what have now become the most costly and inflexible options of the Medicaid program as the primary means of providing services. Specifically these funding options are "rehabilitative services" and Intermediate Care Facilities for People with Mental Retardation (ICF's-MR).

Prior to the development of the Home and Community-Based Services (HCBS)Waivers, the presence of these two options presented a dilemma to states. Their basis in a medical and remedial model of service delivery and their intense level of regulation drive up costs without adding commensurate value to people's lives. States and providers have understandably complained about the inflexibility and unnecessary and costly regulations of these programs from the time they were created. At the same time, most states made a calculated decision to accept these costs and rules as a trade-off for the significant amount of federal funding which they bring. This has been particularly true for Idaho, with its high percentage of federal matching dollars in Medicaid. In fact, Idaho pioneered the creation of the "rehabilitative service" option as an optional Medicaid covered service.

With the development of the HCBS Waivers, and particularly with their evolution in this decade to allow states to craft highly individualized, person-centered and flexible services, states are rapidly replacing the more restrictive and costly rehabilitative service and ICF's-MR options with the less costly and more flexible HCBS waiver services. Idaho has been reluctant to make this conversion. As a result of that reluctance individuals receiving services are served in daytime and in living settings in which their choices are limited and their capacity to use available funding to create more personalized and effective support is virtually non-existent. The consequence of that reluctance for the overall system is a higher than necessary cost of publicly-funded services.

It is important for state and provider agency administrators to rethink the use of these two Medicaid options. People do not need Medicaid covered rehabilitative services, which must by federal regulation be "medical and remedial" in nature. People need meaningful activities to engage in during the day, preferably activities which will generate an income for them. People do not need an ICF-MR. People need a good place to live and support from competent others in order to live there. *There is nothing funded through the rehabilitative services option or the ICF-MR program that cannot be provided more flexibly, at the same or higher quality, and at less cost through services funded by a well-crafted Home and Community-Based Services Waiver.*



A related obstacle to the evolution of Idaho's developmental disabilities services system is the structure and limitations of the current HCBS waiver for people with developmental disabilities. When the federal Health Care Financing Administration (HCFA) first began managing these waivers in the early 1980s, it was a challenge to create comprehensive, flexible, high quality services without mimicking many of the more problematical features of the ICF's-MR or other Medicaid services. HCFA was then still operating from a mindset that Medicaid was, after all, a "medical program" and the waiver needed to function within that understanding.

Neither the waiver nor the concept of self-determination are "anti-provider" initiatives

Since that time, and particularly over the past six years, the waiver programs have evolved to be as person-centered and person-directed as states wish them to be, with the support and encouragement of HCFA. Throughout the country, HCFA has been working as a partner with states to increase the flexibility of the waiver programs, enabling federal and state government to better serve more people and to use Medicaid dollars more effectively. Idaho's waiver program does not appear to have benefited as yet from the federal change in attitude by both Congress and the Executive branch to give states more authority over how they use waivers to create a better system of support for their citizens. As a result Idaho's HCBS waiver for people with developmental disabilities is both challenging to administer for the state and providers, and difficult to understand by consumers.

The final obstacle related to this discussion is the lack of understanding by providers represented by the Idaho Association of Community Options and Resources (IACOR)of the nature of their work. One must assume that the diatribe against the development of home and community-based services developed by IACOR (*The Runaway Train*, dated February, 1998) represents simply a lack of understanding by this association of what has been occurring throughout the country and in Idaho in helping people with developmental disabilities receive the support they need to live good lives in our communities.

The Runaway Train polemic was so full of inadequate information and misinformation that one can be hopeful that the association would be an ally in the creation of a better system of services through obtaining more accurate information about how services are evolving under the waiver programs. Agencies can help themselves and be helped by others to understand the valuable role they can play as providers of services and supports funded through the HCBS waivers. Neither the waiver nor the concept of self-determination are "anti-provider" initiatives.

Recommendations and Potential Next Steps

There are three sets of recommendations listed. The first suggests ways to continue the learning, to build upon what is currently working in Idaho, to capitalize upon the growing constituency of people with disabilities, family members, professionals, advocates and citizens who are committed to learning together how to help all people with developmental disabilities lead better lives in Idaho. The second set of recommendations relates to building upon the growing understanding of the need for people with developmental disabilities and their families to have a greater voice at the policy level, as well as at the personal level. The final recommendations relate specifically to addressing the barriers noted in the section above.

Build Upon What Is Working

- Review pages 6-10 of this report. Look at each of the points which are described as a foundation for self-determination. Decide what can be done to strengthen, encourage, amplify each of those characteristics or conditions. Be specific ... for example, what can be done to strengthen self-advocacy? Which groups, agencies, individuals will take responsibility for acting?

What opportunities might there be with existing funding to help people with developmental disabilities and those who support them use available funding to choose how they wish to have their needs met?

- Many of the foundation characteristics relate to collaboration among people who care about individuals with developmental disabilities. Look at ways to strengthen that collaboration.

- Take what has been learned about how people with developmental disabilities can help create the lives they want within their communities, and find ways to pilot additional opportunities for learning. Look particularly at the learning which has occurred through family support, supported employment, supported living, and the Home of Your Own Project. What opportunities might there be with existing funding to help people with developmental disabilities and those who support them use available funding to choose how they wish to have their needs met?

- Can a small amount of pilot funding for self-determination be obtained, for example, for rural areas? Show what it would look like in Peck, Idaho to have a few people with developmental disabilities create their own lives with a limited amount of funding and the support of others.

- Share information about self-determination with others throughout Idaho. The amount of information available through the Robert Wood Johnson Foundation Self-Determination initiative is growing rapidly through the learning occurring each day in more than 100 places across the country. Contact projects in the neighboring states of Oregon, Washington and Utah.

- Encourage and enlist provider agencies to be part of the learning together. Create opportunities for existing and potentially new agencies to think about how they can enhance their current capacity or create a new capacity to respond with continued competence but greater flexibility to what people with developmental disabilities want and need from them.

Strengthen the Voice of People with Disabilities and Families

- Citizens, legislators, administrators and provider agencies will all benefit from individuals with developmental disabilities and families becoming partners in creating the policies which guide the system of support they rely upon. Time and again, the message about the system from those who receive support is clear: keep it simple ... don't give us things we don't need ... let us help keep the costs down so everyone can get support.

keep it simple ...
don't give us things we don't need ...
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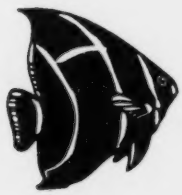
In addition to building upon current efforts, as described above, it is worth paying special attention to ongoing strategies which will strengthen the capacity of people who receive support to inform the discussion of how that support can be provided and paid for. Such strategies might include:

- Expanding and developing leadership among people with developmental disabilities, strengthening current self-advocacy efforts in Idaho, as well as;
    - using the self-determination learning activities being developed for people with developmental disabilities by the Human Services Research Institute;
    - contacting self-advocacy groups in other states to learn from and with them;
    - contacting Advocating Change Together, an organization in St. Paul, Minnesota, which has created an effective workshop in helping self-advocates and their allies work together.

- Expanding and developing leadership among families, building upon current efforts in Idaho, as well as:
    - maintaining the Partners in Policymaking program;
    - organizing "graduates" from Partners
        - in statewide forums
        - in local communities or regions of the state
    - reaching out and connecting with other families and family-based organizations.

- **Statewide forums which will bring self-advocates and families together from across the state to:**
    - create a public process for creating a clear vision, and for planning based upon that vision;
    - create strategies to engage other important system stakeholders in an *ongoing* dialogue over immediate and long term changes for the system of services and supports;
    - help create local and regional agendas and tasks in support of the learning which needs to continue; and
    - create a communications process to inform others throughout the state of the vision, the planning, the dialogue and the actions which will flow from this collaboration.

Revise Medicaid-Funded Developmental Disabilities Services



The current system has severe limitations in both responsiveness to the people it serves, and responsiveness to state and federal taxpayers.

While Medicaid is the dominant funding source for people with developmental disabilities, the key questions related to services for people with developmental disabilities do not yet seem to have been thoroughly addressed within the recent Medicaid reform discussions.

- It is the simple, though perhaps naïve suggestion of this author that the stakeholder groups mentioned throughout this report set aside their historic differences of opinion, accept the premise that they all care both about people with disabilities and the cost of services to those individuals, and learn together how to transform Idaho's Medicaid-funded services to people with developmental disabilities. As described in the section on barriers, the current system has severe limitations in both responsiveness to the people it serves, and responsiveness to state and federal taxpayers.

- Use the growing wealth of information available to inform the discussion over the need to revamp the manner in which Medicaid is used to support people with developmental disabilities in Idaho. Specific sources of information are:
    - The previously noted October, 1992, report entitled *Visions of the Future: Improving Developmental Disabilities Services in Idaho.* This document includes an extensive discussion of the issues related to the use of the rehabilitative service option and the ICF's-MR program.

    - *Medicaid and System Change: Finding the Fit* (February, 1998, National Association of State Directors of Developmental Disabilities Services). This is an excellent document describing the changes in Medicaid policy which are helping states to create more effective Medicaid-funded services and support.

. . . The idea for a pilot of this idea is not new. Just do it.

- Technical assistance from the National Association of State Directors of Developmental Disabilities Services. In working with all 50 states and the District of Columbia, NASDDDS has developed an invaluable expertise in understanding Medicaid options available to states and helping states think through how to best use those options.

- Contact with and assistance from other states. It would be particularly useful for Medicaid staff to contact Medicaid officials in other states which have previously relied extensively on ICF's-MR and rehabilitation services funding and have been replacing that funding with HCBS waiver funding. Two states worth contacting are Michigan and Minnesota.

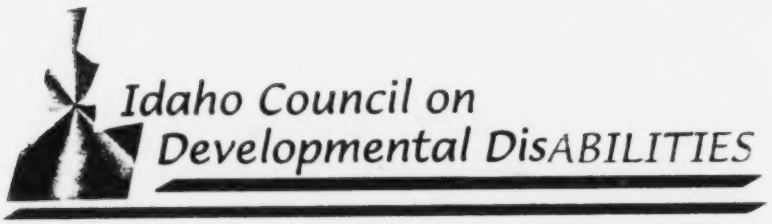
- Contact with providers and provider associations outside of Idaho. Provider agencies and associations (including IACOR) are encouraged to contact the national association to which many of them belong (ANCOR) for more accurate information about the transformation from ICF's-MR to HCBS funding of services, as well as to contact individual providers and provider associations in other states which have been or are engaged in this transformation (again, Michigan and Minnesota would be good places to start).

- Pilot the transformation from ICF's-MR funding to HCBS waiver funding. The aforementioned competence of Medicaid and provider agency management and staff certainly has the potential to learn together how to begin the transformation to a more efficient and effective system for the state, for providers, and for people receiving services. The idea for a pilot of this idea is not new. Just do it.

We are entering a remarkable period in our history. Over the next two years we will be inundated with tales of the end of the Twentieth Century and the beginning of a new millennium. Within the field of disabilities we are moving to this new era with a growing understanding of both what we have achieved to date, and of what we have yet to accomplish.

The ideas represented by the concept of Self-Determination will be part of this new era. How that will happen in Idaho will be created by people with disabilities in the state and by the many citizens, paid and unpaid in Idaho's human services system and communities who care about them.

Jonathan, there really is no question about whether people should have their freedom. The questions are simply, "How will people with developmental disabilities in Idaho obtain it, and when?"



280 N. 8th Street, Suite 208

Boise, Idaho 83720-0280

Telephone: (208) 334-2178

TTY/TDD (208) 334-2179

Toll Free Outside Boise: 1-800-544-2433

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